

indicating reproducibility. Internal consistency was good ( $\alpha$ : Time 1 = 0.87, Time 2 = 0.91). The HOIQ showed evidence of discriminative validity, being able to distinguish between individuals who differed according to self-reported severity of outbreak. **CONCLUSIONS:** The HOIQ represents an effective method for determining the impact of a herpes outbreak. The measure is scheduled to be used on a daily basis during such outbreaks in a trial designed to determine the effectiveness of a new treatment for RGH.

**PIN42**

# **MEASURING TREATMENT-SPECIFIC ASPECTS OF HRQL IN PATIENTS SUFFERING FROM PRIMARY ANTIBODY DEFICIENCIES**

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**OBJECTIVES:** Little is known about the health-related quality of life (HRQL) in patients with primary antibody deficiencies (PAD) and their need of lifelong immunoglobulin G (IgG) replacement therapy. Daly et al. (1991) developed a questionnaire, the Life Quality Index (LQI), consisting of one scale of 15 items related to IgG treatment. The higher the score, the better the treatment-specific HRQL. The construct validity has never been shown, nor has the instrument been related to patient-reported data. **METHODS:** Of 58 patients (17 children, 41 adults) with PAD were treated with weekly IgG infusions (Beriglobin P, Aventis Behring, Marburg) for 10 months. Beside other instruments, the patients answered the LQI and a single-item related to their change in health status at baseline, 6- and 10-months. Construct validity was evaluated using explorative factor analysis using the Kaiser criterion and a varimax rotation. For the evaluation of clinical validity an anchor-based approach was applied, i.e. the patients' self-assessments of their health-status changes over time were related to LQI changes over time. **RESULTS:** There was a noteworthy improvement for 9 LQI items in adults and for 12 LQI items in children from baseline to 10-months. Exploratory factor analysis suggested a 3-factor solution that accounted for 52% of the total variance. For patients reporting an improvement in their health status, all mean changes in LQI scores were positive, and in 10 of 15 items changes larger than 0.5 were observed. Thus, an improved self-perceived health led to improved LQI scores. **CONCLUSION:** The LQI is well suited to capture treatment-specific aspects of HRQL in patients with PAD receiving IgG. The items could be aggregated into three sub-scales. The anchor-based approach indicates that the LQI may serve as a valid instrument to assess the patients' perceptions of their treatment.

**NEUROLOGICAL DISORDERS/MIGRAINE**

# **NEUROLOGICAL DISORDERS/MIGRAINE—Clinical Outcomes Studies**

**PNN1**

# **CARE OF PARKINSON'S DISEASE PATIENTS IN EUROPEAN COUNTRIES; EUROPEAN COOPERATIVE NETWORK FOR RESEARCH, DIAGNOSIS AND THERAPY OF PARKINSON'S DISEASE (EUROPA)**

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**OBJECTIVE:** To evaluate the different European health care structures involved in the care of Parkinson's disease (PD) as well as the economic impact of PD in European countries (EC). **METHODS:** Data are generated by desk top research (contacting national medical societies, PD specialists, institutes for statistics, third party payers, ministries, support groups and conducting structured database search). Reviewed data are: national treatment guidelines and treatment patterns, hospitalization, rehabilitation, disease management programs and availability of support groups. Epidemiologic data were elaborated by systematic literature review. **RESULTS:** 1) In France and the Czech Republic patients are mainly treated by neurologists, while in Sweden patients are preferably under care of General Practitioners. 2) Treatment guidelines are not standardized in Europe. 3) PD rehabilitation is differently organized in the EC, however, paucity of data precludes a detailed statement. United Kingdom (UK) PD society is developing a network of PD specialist nurses to co-ordinate multidisciplinary care, while in Germany and other EC no disease management programs exist. Total annual costs for PD differ: UK \$280 million (Haycock, 1995), France \$411 million (LePen, 1999), Sweden \$136 million (Hagell, 2002) and Germany \$1.0 billion (Dodel, 1998). Direct medical costs account for 20–40% of total costs depending on the Health care system, indirect costs account for approximately 22–50% of total costs in the UK (McMahon, 2000), Sweden (Hagell, 2002), and Germany (Spottke, 2002), respectively. Average length of stay differs among the EC (Germany 21.1 d, UK 29.4 d, France 19 d and Italy 16.4 d). **CONCLUSION:** PD care seems to be managed differently in the EC analyzed. Despite the importance of the disease detailed data are not easily accessible. One of the aims of EuroPa is to gather this information and optimize therapy for PD on an European level. These data are crucial for a cost effective and optimized therapy for PD patients.